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# Some *AIDS* Advocates Now Question Need for Special Services

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By SHERYL GAY STOLBERG

**N**EW YORK -- Behind the swinging glass doors that welcome visitors to the Gay Men's Health Crisis is a world where *HIV* is not just a deadly virus, but also a ticket to a host of unusual benefits.

At the center, the nation's oldest and largest *AIDS* social-service agency, almost everything is free: hot lunches, haircuts, art classes and even tickets to Broadway shows. Lawyers dispense advice free. Social workers guide patients through a Byzantine array of government programs for people with *HIV*, and on Friday nights dinner is served by candlelight.

The philosophy underlying the niceties and necessities is "*AIDS* exceptionalism." The idea, in the words of GMHC executive director Mark Robinson, is that "*AIDS* is special and it requires special status." That is a concept that has frequently been challenged by advocates for people with other *diseases*.

Now some advocates of people with *AIDS* are quietly questioning it themselves.

With death rates from the *disease* dropping for the first time in the history of the 16-year-old epidemic, the advocates suggest, it is time to re-examine the vast network of highly specialized support services for people with *HIV*.

Some people are growing increasingly uncomfortable with government's setting aside money for doctors' visits, shelter and drugs for people with *AIDS* while not operating comparable programs for other *diseases*.

"Why do people with *AIDS* get funding for primary medical care?" Martin Delaney, founder of Project Inform, a group in San Francisco, asked in an interview. "There are certainly other life-threatening *diseases* out there. Some of them kill a lot more people than *AIDS* does. So in one sense it is almost an advantage to be *HIV* positive. It makes no sense."

Delaney, a prominent voice in *AIDS* affairs since the onset of the epidemic, is calling on advocates to band with people working on other *diseases* in demanding that programs for *AIDS* be replaced with a national health care

demanding that programs for *AIDS* be replaced with a national health care system.

He complained that organizations like the Gay Men's Health Crisis had been "bought off" by the special status given to *AIDS*. "We took our money and our jobs," he wrote in the Project Inform newsletter in the summer, "and we dropped out of the national debate."

That criticism has not won many fans within "*AIDS* Inc.," as some call the cottage industry of agencies that care for *HIV* patients. But Delaney's article, "The Coming Sunset on *AIDS* Funding Programs," has set off an intense debate.

"I think Delaney knows that he is putting out a provocative, stimulating kind of discussion," said Jim Graham, executive director of the Whitman-Walker Clinic in Washington, a counterpart to the Gay Men's Health Crisis. "This is the whole discussion about *AIDS* exceptionalism. I think *AIDS* is an exceptional situation. *AIDS* is caused by a virus. That infectious virus is loose in America. And when you have a virus, an infectious situation such as this, it takes an exceptional response."

Yet many people involved with *AIDS* say some change is in order. Many programs created in response to the epidemic were intended as stopgaps, to help the dying in the health emergency. Some of the money that pays for free lunches at the Gay Men's Health Crisis, for instance, is from the Federal Emergency Management Agency, which usually works on natural disasters like hurricanes and earthquakes.

But it is becoming clear that the *AIDS* crisis is long term. New treatments may soon turn the *disease* from a certain death sentence to a chronic manageable illness. Accepting the projection that the epidemic will last for at least another generation, advocates say, the government and private agencies need to take a hard look at spending in the coming years.

"We are not going to die, at least not all of us, and at least not all so soon," said Bill Arnold, co-chairman of the ADAP Working Group, a coalition in Washington that is lobbying the government to add money to its *AIDS* Drug Assistance Program. "A lot of us are saying that the *AIDS* network or *AIDS* Inc. or whatever you want to call it, this whole network that we have created in the last 15 years, needs to be reinvented. But reinvented as what?"

That question is provoking considerable anxiety among employees at the estimated 2,400 service agencies in the United States, several hundred of which are in New York City.

The agencies offer an array of services from sophisticated treatment advice to free dog walking. Although most are tiny, some have grown into huge institutions financed by federal, state and local government dollars, as well as contributions.

Critics say the organizations cannot possibly re-examine themselves because they have become too dependent on the government. "They have all become co-opted by the very system that they were created to hold accountable," said playwright Larry Kramer.

He founded the Gay Men's Health Crisis in 1981, but has long been critical of the group. "It's staffed with a lot of people who have jobs at stake," he said.

With 280 employees and 7,000 volunteers, the program is the biggest and busiest agency of its kind. For many with human immunodeficiency virus, the organization and its lending library, arts-and-crafts center and comfortably decorated "living room," offer a home away from home, a place where, as one participant said, "your *HIV*-status is a nonevent."

Craig Gibson, 31, of the Bronx, is one of 10,000 people a year who seek services there. Several days each week, he goes to the living room to play cards after lunch. "You come here, you see your friends," he said one afternoon. "Today they had a great chicken parmesan."

A walk through the lobby shows the power and success of *AIDS* philanthropy. A huge plaque in the entryway lists dozens of donors who have contributed \$10,000 or more, including three who have given more than \$1 million. Even so, 19 percent of the \$30 million annual budget comes from government sources, according to Robinson.

"We still need this extraordinary short-term help," he said.

But he said he was aware that the financing might not last forever. Even as the organization expands, it is doing so with an eye toward eventually scaling back. It just spent \$12.5 million to renovate its new headquarters in a simple but expansive 12-story brick building on West 24th Street.

Robinson, a former accountant, said the building was designed so that any other business could easily move in. The lease is relatively short, for 15 years.

The agency, he added, has realized that it cannot afford to be all things to all people. Until recently, Robinson said, "anybody with *HIV* or *AIDS* could walk into our advocacy department, and virtually anything that was wrong with their life was addressed."

"If they were having problems with their landlord," he said, "we would deal with it. If they needed an air-conditioner, we would deal with it. Now we are really trying to focus on what is specifically related to *AIDS*."

To understand why Robinson and others say they believe that *AIDS* deserves special status, a person has to go back to the response to *AIDS* in the days when it was known as the "gay cancer." The government and the rest of society all but ignored the illness, forcing the people who were affected -- by and large homosexuals -- to fend for themselves.

"The original reaction," Arnold said, "was in response to: 'This is not our problem. We don't like you. Go away and die.'"

"By the time you have got 200,000 to 300,000 people dead, they all have friends. They all have relatives. That's a lot of people impacted. So now you have some critical mass."

That mass has translated into a political force -- and significant federal money. In his budget proposal for 1998, President Clinton has asked Congress to allocate more than \$3.5 billion for *AIDS* programs, including \$1.5 billion for *AIDS* research at the National Institutes of Health and \$1.04 billion for the Ryan White CARE Act, which provides medical care, counseling, prescription drugs and dental visits for people with *HIV*.

If Congress enacts the plan, *AIDS* spending would increase 4 percent over last

year, and 70 percent over 1993, when Clinton took office.

In a paradox, some doctors say the array of services makes it harder to care for people whose behavior puts them at risk for *AIDS*, but who are not yet infected.

"We're trying to figure out how to provide services to *HIV*-negative people to help them stay negative," said Dr. Michelle Roland, who treats indigent patients at San Francisco General Hospital. Many of her patients are drug abusers, people at high risk.

"The truth is," Dr. Roland said, "we have a lot more access to resources for *HIV*-positive people for drug treatment, education and housing."

While advocates for people with other *diseases* often lobby vociferously for more money for research, the notion of exceptionalism -- that a particular illness deserves special government status -- is unique to *AIDS*, and it is generating a backlash.

For years, the American Heart Association has gone to Capitol Hill budget hearings with charts showing that more research money was spent per patient on *AIDS* than on heart *disease*. Advocates for people with Parkinson's *disease* have done the same.

It will not be long, Delaney argues, before people with those and other *diseases* follow suit, demanding Ryan White-style programs for themselves.

Some authorities, including the president of the American Foundation for *AIDS* Research, Dr. Arthur Ammann, said Delaney was correct in pushing for universal health care. "We've got to form an alliance with these other *diseases*," Ammann said, "and say none of us is going to get adequate health care the way the system is going."

But others call Delaney naive. "It's interesting to muse about what he says," said Graham of the Whitman-Walker Clinic. "But it's both undesirable and impossible. So what's the point of talking about it?"

Naive or not, in challenging exceptionalism Delaney has clearly broken a taboo.

"We sort of question it among ourselves behind closed doors," said Mark Hannay, a member of the New York chapter of Act Up, the *AIDS* Coalition to Unleash Power. "Like, isn't this nice, but we're the only ones getting it."

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